SUMMER 2023

A MAGAZINE FOR KIDS WHO HAVE CF AND YOUNG CARERS

ROZEE

All about nebulisers...

Virtual catch-ups

What is Gratitude?

An AWESOME Sibs camp!

CYSTIC FIBROSIS
Western Australia

ALL AWESOME!

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Editor's Letter

Welcome to this year's edition of ROZEE Magazine!

This edition is packed full of great stories, articles and fun activities.

We see a Day in the Life of Sam, Kiah talks about starting Trikafta, Emily shares her experiences joining the Virtual Catch ups for CF Kids, the Anderson siblings review the MyABCF Book, Millie talks CF and school and we meet Ivy, a CF sibling.

There's also sibling event wrap ups and photos and lots of fun activities too like making yarn letters, a puzzles and jokes section and how to make mini pizzas.

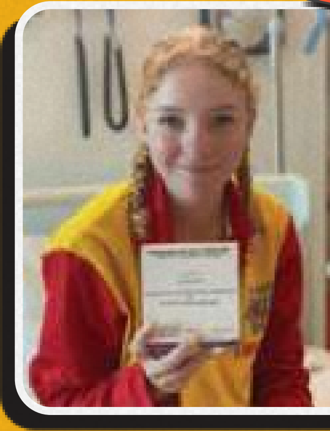
Thanks to Sam, Kiah, Emily, Oli, Ruby, Lucy, Millie and Ivy for being a part of the 11th edition of Rozee and sharing a bit of your lives with everyone.

Bye for now,

Gillian

CONtEnTS

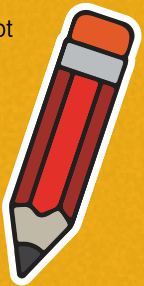
ASK...KIAH!
ABOUT STARTING TRIKAFTA



Hi Kiah, can you tell us a bit about yourself?

Hi, my name is Kiah. I have CF and have just turned 17. I live with my Mum and Dad and my eight-year-old brother, who also has CF. I am in year 12 this year and I am Head Girl at my school. My favourite subjects are Business and Enterprise and Art. I am also studying a diploma of commerce at TAFE and hoping to study marketing psychology at uni next year.

I work at Adventure World as a lifeguard – I absolutely love my job and the people I work with – it is so much fun! I also run my own business making dog accessories (when I am not sick or working or studying) and I love to draw. I have an 18-month-old border collie x koolie, called Splash who I am training as an assistance dog and who I like to make lots of pretty accessories for. I have recently bought my own little car and hoping to get my driver's license soon!

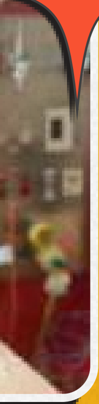


How were you feeling about starting Trikafta?

I was very nervous and excited about starting Trikafta. I had also heard about some side effects and given that I have reacted to so many antibiotics in the past I was very worried that I would react to Trikafta and or have bad side effects. I was also very worried that it simply wouldn't work for me.

What results have you noticed so far?

I think that I have had pretty good results with Trikafta. Within a few hours my cough changed, and I could feel things shifting in my lungs. I was asked to do lung function on day five and when I did it, I thought that my home spiro was broken. It showed a 30% increase in my lung function!



Since then, I have noticed that I can now eat without feeling gross and I can laugh without coughing. In fact, I hardly cough at all now and so I have less headaches, I sleep better, and I have more energy. I have also gained back some weight that I had lost when I was sick.

I also have more energy. I don't need to nap in the afternoons anymore (don't tell mum) and can do so much more in my day. I have also noticed that I don't crave salt as much as I used to, and I don't get all salty after I exercise anymore.

Have there been any difficult side affects you weren't prepared for?

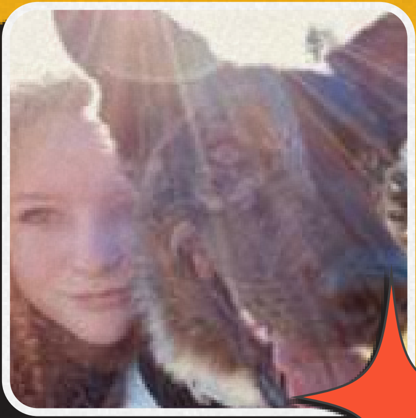
At first, I felt very unwell with a lot of nausea as my body adjusted to being on Trikafta. I also had a bit of a rash on my feet and legs for the first few days. I was given an antihistamine which helped to settle this and then the rash disappeared on its own a few days later. I have also never felt so hungry in my life!!

Has anything else changed in regard to your CF treatment?

While I still take all my regular CF meds (Creon, salt, vitamins etc) and still do my physio, I have not needed antibiotics and have been feeling really great. While these regular treatments may not change, they feel like less of a burden because I'm feeling so much better, and it doesn't take so much energy to do them.

What are your dreams for the future?

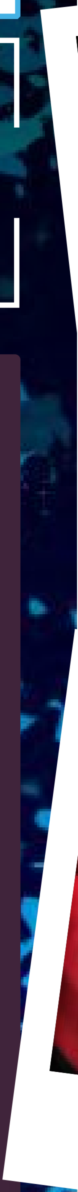
To rule the world. Just kidding. One day I'd like to be running my own successful business. I am keen to finish school and my diploma and to be able to study marketing psychology at university next year. I am keen to travel and do all the things I wasn't sure I would be able to do, but now can.



Just being able to dream and plan for the future is a blessing and knowing that I can do these things without worrying so much about being unwell or becoming unwell is a wonderful experience in itself.

A DAY IN THE LIFE OF

SAM



Hi, my name is Sam and I am 11 years old. I live with my Mum, Dad, older brother David and younger sister Charlotte. I love sports, playing the trumpet and video games. Here is a day in my life...

ON MONDAYS

5:30am	Wake up time! I then play about one hour of video games.
6:30am	Physio. I have a PEP mask and a yellow resister that I do for 20 minutes.
7:00am	Breaky time. I eat three pancakes with maple syrup. I also take enzymes, Orkambi®, vitamins, salt and another medicine called Posaconazole®.
8:00am	I do trumpet practice for 15 minutes. I do this five days a week.
8:30am	Now I am going to school where on the current day, Monday, I have sport which is my favourite subject.
11:00am	I have lunch and also take my enzymes. Then I'm going to play soccer with my friends.
1:40pm	Now it's recess time where I will play some ping pong with my friend.
3:00pm	I am going home to my family.
6:00pm	Time for volleyball.
7:00pm	Finished volleyball and having a shower after a stressful day.
7:30pm	Dinner. Tonight I had bowls of brown rice, oil, salt and small chocolate milks for dessert (plus all my tablets).
8:00pm	I am going to bed for some well needed sleep.

TRUMPET PRACTICE

MY FAMILY

VOLLEYBALL!!

PHYSIO TIME

ME AND MY SISTER, CHARLOTTE

GAMING

all·about...
NEBULISERS

A nebuliser, or neb for short, is a machine that helps you take your medicine by turning it into a mist that you can breathe in. This is important as the medicine gets to the lungs and starts working quickly

What Can You Nebulise?

There are lots of different types of medicines that you can nebulise, some of them treat infections in the mucus and others help thin the mucus so it is easier to cough up. Other medicines might help open up your airways or reduce the swelling or inflammation in your lungs. It is important to remember that you only use your nebuliser for one medicine at a time – it might take a bit longer than you would like but some of the medicines stop working if you mix them together.

Types of Nebs

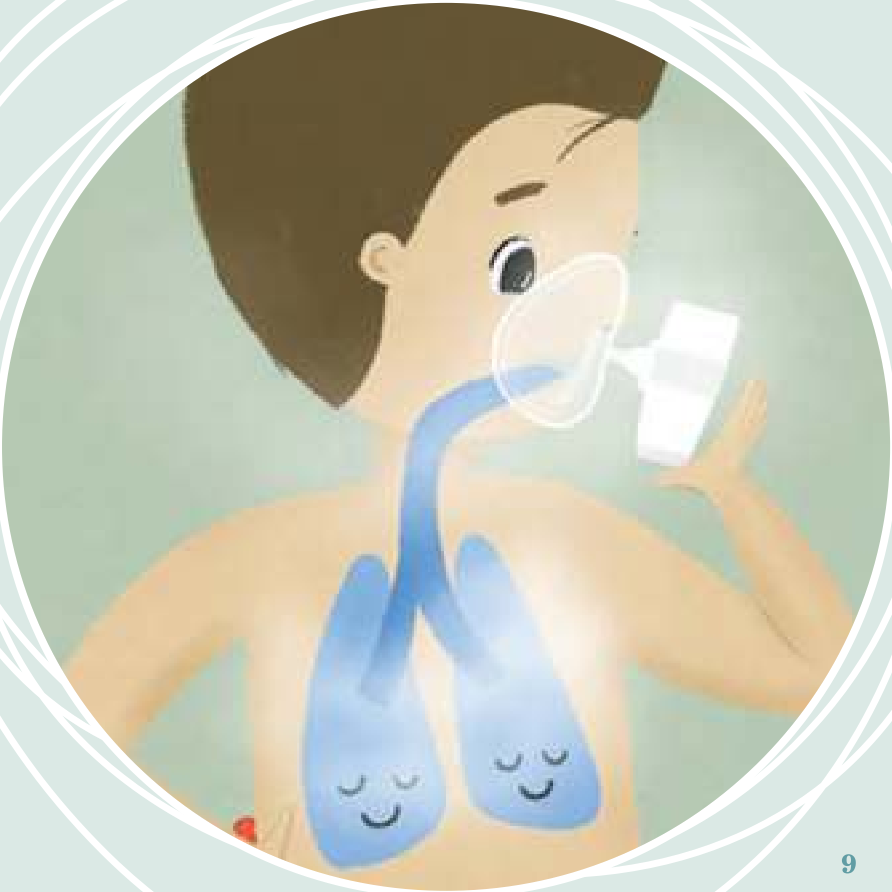
There are also lots of different types of nebulisers, some are very loud, and some are almost silent, some are big and some are small, some plug into the wall and others can be used anywhere like in a car or in a tent. You might use a mask with your nebuliser or a mouthpiece with a nose peg. Some people use a mouthpiece on its own once they have learned not to breathe through their nose!

What If I Need a Nebuliser?

If you need a nebuliser, your CF team will choose the right one for you and show you how to use it. It is really important to clean it every time you use it, so it keeps working well and make sure it is nice and dry before you pack it away. Your mum, dad or another adult can help you learn how to do it properly.

When Do People Use a Neb?

You might use your neb as part of your physio, or when you wake up in the morning or before you go to bed. Some people give their neb a special name and use it four times a day! Nebulisers are pretty useful, and even though everybody does it a bit differently, lots of people use them to help keep their lungs healthy.

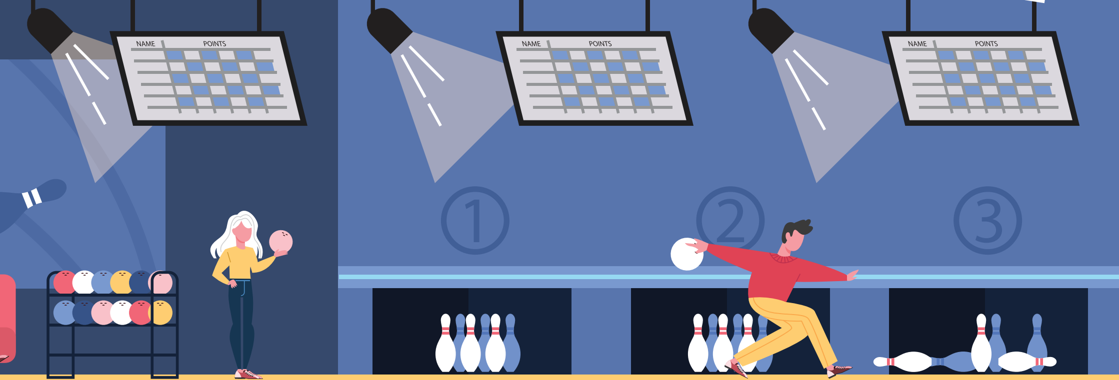


SIB'S DAY OUT

We had a great time at our Sib's Day Out early this year. We spent the afternoon at Zone Bowling having so much fun and making friends. Everyone got to play a couple of games of 10 pin bowling, enjoy a yummy lunch and test their skills playing the arcade games!

We have some very talented (and competitive haha) gamers in our group!

This event happens each year and we always do something different and fun. We have previously been on a river cruise and to the zoo. Our next Sib's Day Out is happening early next year. We will be sure to send your parents more information about it closer to the time.



Talking to someone

Having CF or having someone in your family with CF can be hard sometimes. If you would like to talk to someone about your feelings, you might like to meet Haylee, our Youth Social Worker.

Haylee's job is to work with children and young people to help them feel happy and healthy. She can help you talk about your feelings and any worries you may have.

It is normal to feel frustrated, upset, and sad sometimes and it can help to have a person who can listen and provide healthy activities so that you can feel happier.

You can ask Mum or Dad to reach out to Haylee on haylee.riddell@cfwa.org.au to find out more.

MEET THE SIBLING

IVY

Ivy has two older siblings, Oliver who is 12 and has CF, and Hayley who is 18.

Hi Ivy, can you please tell us a bit about yourself?

Hi! I'm Ivy. I just turned seven years old in October. We have two cats called Barbie and Gomez.

What's your favourite thing to do in your spare time?

Playing Minecraft, going fishing with my dad, wearing fancy make up and playing with playdoh!

Ivy with red hair for 65 roses month!

Is it hard sometimes having a sibling with CF?

Yes, since Covid started.

What are some things you like to do if you're feeling a bit sad or worried about your sibling?

Usually I hug him or sometimes I have a cry on my bed with my pillow.

Do you have any tips for other kids with someone with CF in their family?

Love them and help them be happy!

What are some of the good things having a sibling with CF has taught you?

Learning about germs and to move away from someone if they are sick.

Do you think you might like to come to Sibs Camp when you're old enough?

YES!!! To toast marshmallows on the campfire!

MY ABCF BOOK

Have you seen the new book we have written? It's made just for kids with CF and their family.

My ABCF follows our two special friends as they journey through the alphabet learning all about CF! The friends in the book both have CF too. Read along as they learn more about CF and things like enzymes, medicines, nebulisers, feelings and much more.

We chatted with siblings Oli, 8, Ruby, 6 and Lucy, 4 about what they think of the book. Oli and his little brother Jimmy, 2, both have CF.

What do you think about our new book, My ABCF?

Oli -
It's full of information about CF and things I do like doing my physio with the abacus and PEP tube and going to the hospital. I like the pictures and love spotting the roses on each page!

Ruby & Lucy -
We really like the book because it's about CF and our brothers have CF.

Which is your favourite page and why?

Oli -
The best page is the feelings page. It has all of the feelings and pictures of it. It makes me feel good because I feel those different feelings and it says it's okay.

Ruby & Lucy -
Lucy loves the koala cuddle page because she loves cuddles with Mum and Dad! Ruby loves the 65 Roses page because she loves roses.

Is it helpful to read about other kids with CF?

Oli -
I like seeing other kids who have CF in the book because it makes me feel less lonely.

Ruby & Lucy -
It's nice to know other kids have CF like our brothers.

Did you learn anything new?

Oli -
I learnt that people without CF have enzymes and they come from their pancreas.

Ruby & Lucy -
We liked the bugs on the hands! They were colourful and pretty.

Did the book encourage you to talk with your mum and dad about anything?

Oli -
The feelings page helped me talk about how I'm feeling about going into hospital and that it's okay to be scared.

Ruby & Lucy -
We talked about how the body works and what's inside and how Oli and Jimmy's bodies work differently to ours.

If you don't have a copy of this book yet, ask mum or dad to email gillian.hoyland@cfwa.org.au to get a free copy. Or extra copies are available on our website shop.

What is Gratitude?

Have you heard of gratitude before? Gratitude is where we stop to think about things that we're thankful for.

We can practice gratitude by pausing to appreciate the things that we might often take for granted, like having a place to live, food, clean water, friends and family. It's taking a moment to reflect on how fortunate we are when something good happens – whether it's a small thing or a big thing.

Sometimes, feelings of gratitude just happen! But we also can create feelings of gratitude by deliberately thinking about things we're grateful for.

If you're having a bad day or not in a great mood, feeling grateful can be hard. It's important to find the good in hard days too. Something small, like being thankful for a sunny day or for a nice flower.

You can build a gratitude habit just by paying attention each day to things you're glad to have in your life. Slow down and notice what's around you.

You might even like to write it down in a gratitude journal. It doesn't need to be fancy. Just a notebook where you can write a few things you're grateful for every day. Practicing gratitude regularly is good for your overall wellbeing, and can help with stress and worries. It can even help your physical health, how well you sleep, and your relationships with your family and friends.

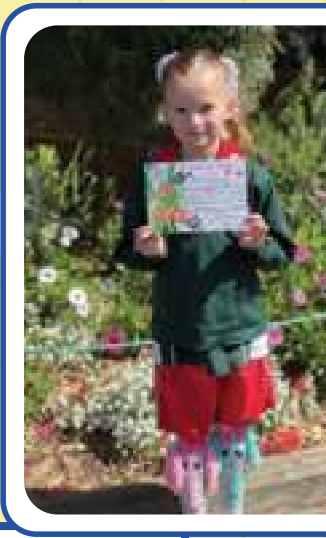
my gratitude tree

You can have a go at practising gratitude now by filling in the gratitude tree below.

What are some things you're grateful for?
Can you fill the tree with 10 things
you're grateful for right now?

CF AT SCHOOL WITH…

MILLIE!



Millie is a happy seven-year old who loves spending time with her friends. We chatted with Millie to ask her a few questions about school and living with CF.

Hey Millie, can you please tell us a little bit about yourself?

I am seven years old and in year two. My favourite subject is maths because it is fun. I love school because I get to see and play with my friends. I also love to do arts and crafts and enjoy roller skating.

How would your friends describe you?

That I am kind and Addison (my friend) always says I am funny.

What are some of the trickier things about having CF at school?

Everyone asks questions like "why do I have to take tablets?" It's annoying. I miss my friends when I have to go to hospital.

How do you manage CF at school?

I take my Creon with my lunch and recess, and I am allowed to have a water bottle with salt in it on my desk.

I always wash my hands and move away from people who have sniffles.

I have all my own pencils and scissors and do not share my stuff.

I take my own water bottle as water fountains are yucky.

There is always hand sanitiser in my classroom. Everyone has to use it before going into class.

The teacher tells us to cough and sneeze into our elbow.

The teachers tell you to stay home if you are sick.

What would you tell kids who may be worried about starting school with CF?

Not to worry and that everybody is different. I would tell them that I have CF and go to school.

What would you like to be in the future?

A vet. I love animals.

Anything else you would like to add?

School is fun and you meet a lot of kind people and get to learn new things.

another awesome SIBLING & OFFSPRING CAMP

Our Sibs Camp this year was held at Point Walter Recreation Camp. We had 22 kids come along for the two-night camp.

They had heaps of fun doing all the awesome and challenging activities like mini golf, team games, archery, flying fox, abseiling, kite making and more. The kids also had a great time hanging out and making friends with others who know what it's like to have someone with CF in their family.

The camp runs every September school holidays for kids with a brother, sister or parent with CF. If you think you'd like to come next year, ask your parents to let us know.

Big thank you to

lotterywest

hbf

VIRTUAL CATCH UPS FOR KIDS WITH CF

WITH EMILY!

At the start of the year, the CFWA team started running online catch ups for kids with CF aged between 6 and 12 years.

The sessions last about 30 minutes and are run by two of our team members, Mel and Haylee. In each session, everyone is given the opportunity to do a show and tell or talk about what's been going on in their life. We might chat about dealing with CF, share physio stories, talk about school and friends, meet each other's pets and much more. It is a very relaxed, fun and safe way to meet and make friends with other kids with CF.

Emily has attended a few of our Virtual Catch Ups, so we thought we would ask her a few questions about it all.

Hi Emily, can you tell us a bit about yourself?

Hi, I'm Emily. I'm 10 years old and in year five. My hobbies are singing, dancing, exercise, and the subject drama.

Your dad first suggested the Virtual Catch-Up idea to CFWA staff. Why do you think he had this great idea?

I think my dad had a great idea because it gives children with CF the opportunity to meet older and younger children with CF.

Kids having a hard time dealing with CF will have a chance to feel more connected to the other kids on the video call.

What would you say to other kids who were thinking about joining in but may be feeling a bit shy?

It is a very fun 25-minute chat with kids older than you and younger than you. Come out of your comfort zone and try something new.

Not everybody starts life as the most confident person ever, it takes practice, and practice makes progress.

What are some of the things you have chatted about during the catch ups?

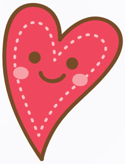
It varies from school, and how to manage taking your Creon, to where you want to go on your school break. We introduce ourselves and have a lot of fun talking to each other.

If you would like to attend a Virtual Catch Up, ask mum or dad to email **mel.tibbitts@cfwa.org.au** to find out the session times.

GET CREATIVE!

You can make it a theme, such as the colours of a sports team, Christmas themed or someone's favourite colours.

You could also cut out shapes or objects rather than a letter such as a star or a Christmas tree.



Thanks to Art Bar for this great idea!

www.artbarblog.com/yarn-wrapped-cardboard-letters

yarn-wrapped letters

Looking for a fun, crafty activity to keep you busy these school holidays? These cute yarn-wrapped letters are a great, simple activity you can do at home and make to suit your own style. Make one for your bedroom, for a friend or as a decoration to hang on the Christmas tree.

YOU WILL NEED:

- A parent or adult helper
- Cardboard
- Sharp scissors or knife with a cutting board
- Yarn (available in local craft stores, such as Spotlight and often in the grocery store)
- Masking tape

HOW TO MAKE IT:

1. First off, you will need to draw the letter you want to create onto thick cardboard. It needs to be in thick bubble writing. You might like to have an adult help with this.
2. Then an adult will need to help you cut out the letter. This can be done with sharp scissors or craft knife, such as an exacto or Stanley knife.
3. Once you have your letter cut out ready to go, you can pick a colour yarn you want to start with and cut a long piece.
4. Tape the end of the piece to the back of the letter with masking tape and then starting wrapping around and around the letter.
5. When finished with that piece of yarn, again tape it to the back of the letter. You can use as many different coloured yarns as you wish and be as creative as you like.

Make-A-Wish®

AUSTRALIA

If You Could Wish for Anything, What Would It Be?

That's the question the Make-A-Wish team ask every child - to spark imagination, to encourage them to dream, and to start making the impossible possible.

The Make-A-Wish foundation grant wishes to kids will many illnesses, including CF. So, if you're between the ages of three and 18 and have CF, you're eligible for your very own wish!

Wishes can be just about anything you can imagine- a shopping spree, meeting your favourite sports star, going on a holiday, getting a new iPad, a cubby house, a pet and so much more (with mum and dad's agreement of course!!).

If you are interested in having your very own dream come true, get mum and dad to have a look at the Make-A-Wish website

www.makeawish.org.au.

GO RED FOR CF

Dress in RED to show your support!

Going red for CF is a great way to fundraise and raise awareness of CF in your school or community group.

York Childcare Centre went red for CF- the kids and staff wore red, they did red baking, red paintings and hand made red roses.

You might like to have a Go RED Day at your school where everyone wears red for the day and brings in a gold coin donation to help raise awareness and funds for people living with CF.

If you would like more information, you can talk to mum or dad about it and read more on our website www.cfwa.org.au/get-involved/fundraising

HOW TO MAKE...

ENGLISH MUFFIN PIZZAS

This quick and easy pizza hack is so simple and yummy! A great after school snack or weekend lunch.

INGREDIENTS

English muffins
Pizza sauce
Grated mozzarella cheese
Toppings - ham/pepperoni, tomatoes, capsicum, pineapple, mushroom, herbs - whatever you fancy!

METHOD

1. Heat the grill (get an adult to help you with using the oven)
2. Cut the muffins in half and place on a baking tray with baking paper
3. Spread the pizza sauce
4. Add cheese and toppings of your choice
5. Cook under the grill for five or so minutes, keeping a close eye on them. Cook until cheese is melted

!! MAKE SURE TO ASK YOUR PARENTS FOR HELP CUTTING THE INGREDIENTS AND USING THE HOT GRILL.

YUMMY

YUMMY

YUMMY

YUMMY

YUMMY

YUMMY

QUICK QUIZ

1. How many colours are there in a rainbow?
2. Which is the largest planet in the solar system?
3. Which big cat is the largest?
4. Whose nose grew longer every time he lied?
5. What is the name of Harry Potter's owl?
6. How many days are there in a year?
7. Who sings the song 'Shiny' from *Moana*
8. What is a group of lions called?
9. Which AFL team won the 2022 Grand Final?
10. How many sides does an Octagon have?

ANSWERS: 1. Seven (7) 2. Jupiter 3. Tiger 4. Pinnochio 5. Hedwig 6. 365 7. Tamatoa 8. A pride 9. Geelong Cats 10. Eight (8)

JOKES

Why don't ants get sick?

Because they have tiny antibodies!

What is a really sad strawberry called?

A blueberry!

What is a little bear with no teeth called?

A gummy bear!

How do all the oceans say hello to each other?

They wave!

What do you call cheese that isn't yours?

Nacho cheese!

Did you enjoy reading ROZEE? Do you have CF or have a family member with CF? Do you have a story to tell? Let us know and you might just see yourself in the next issue of ROZEE Magazine!

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